

1 DATE

2 The Honorable Thomas E. Price, M.D.
3 Secretary
4 Department of Health and Human Services
5 200 Independence Avenue, S.W.
6 Washington, D.C. 20201
7

8 **Re: Recommendations on Maximizing the Value of HealthData.gov**

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10 Dear Secretary Price:

11 This letter summarizes the findings of an accompanying National
12 Committee on Vital and Health Statistics (NCVHS) report entitled "**Recommendations**
13 **on Maximizing the Value of HealthData.gov**" regarding the value of HealthData.gov
14 and opportunities for its enhancement. NCVHS is your advisory committee on health
15 data, statistics, privacy, and national health information policy.

16 HealthData.gov facilitates the discovery, access, and use of publicly available
17 health data by providing a searchable online directory of data resources across all HHS
18 operating divisions and several state and municipality open data portals. These data are
19 released to the public under stringent privacy, security, and confidentiality protections.
20 They are subsequently used by a diverse set of stakeholders to contribute solutions
21 towards HHS and state government objectives such as identifying quality gaps and health
22 care inefficiencies, enabling researchers to make scientific discoveries, providing
23 communities information about their health problems to inform their community planning
24 efforts, and fostering innovation by entrepreneurs such as for development of applications
25 to search for physicians.

26 Since its development in 2010, HealthData.gov has expanded to reflect over 3,000
27 datasets in diverse areas of clinical outcomes, administration, and monitoring and
28 evaluation.¹ From 2013 to 2016, web traffic steadily increased from 17,561 to 178,334
29 visitors annually, and the number of sessions doubled from 508,705 to 1,168,138.² Data
30 that are currently catalogued in HealthData.gov and discovered through HealthData.gov
31 or other open data portals are being used to provide medical consumers with more
32 accurate information on local physicians providing the best valued healthcare
33 treatments,³ document disparities in the median cost of orthopedic surgeries and
34 appendectomies between hospitals,⁴ illustrate that incorrectly estimating hospitals' costs
35 caused Medicare to overpay hospitals by \$2.6 billion,⁵ among numerous examples.
36 HealthData.gov has cultivated a health data ecosystem comprised of application
37 developers, community groups, private industry, and other entrepreneurs. After a
38 thorough review of the current status of HealthData.gov, NCVHS offers the following
39 recommendations to further its potential and enhance its utility:

40 **1. HHS should develop an integrated and coordinated strategy within its operating divisions
41 to advance the HealthData.gov vision and mission.**

¹ Examples include: disease surveillance and mortality data (e.g. Drug Abuse Warning Network (DAWN); Surveillance, Epidemiology, and End Results (SEER) cancer registry; and Nationally Notifiable Diseases Surveillance System); health care access, cost, and quality data (e.g. Medicare Preventable Hospitalizations, HCUPNet query system of publicly available all-payer health care databases; Minimum Data Set Quality Indicator Report; and address tool to locate Health Professional Shortage Areas); and consumer-oriented topics (e.g. Household Products Database on the health safety of consumer brands; Genetics Home Reference on genetic conditions; and DailyMed compilation of pharmaceutical package inserts).

² From NCVHS Data Access and Use Work Group analysis of HealthData.gov Google Analytics data, February 2017.

³ Lyons L. U.S. News and RowdMap, Inc. team up to help patients make more informed health care decisions. <http://www.usnews.com/info/press-room/2016/01/19/us-news-and-rowdmap-inc-team-up-to-help-patients-make-more-informed-health-care-decisions>. Published January 19, 2016. Accessed January 12, 2017.

⁴ Crain's New York Business: Health Pulse Extra. January 8, 2014.

⁵ Weaver C, Mathews AW, McGinty T. Medicare overpays as hospital prices rise. *Wall Street Journal*. April 15, 2015. <https://www.wsj.com/articles/medicare-overpays-as-hospital-prices-rise-1429151451>. Accessed February 3, 2017.

42 **2. HHS should implement evaluation and performance metrics and solicit data customers'**
43 **input regularly to increase the use and usefulness of HealthData.gov for diverse consumers,**
44 **support the work of HHS staff, and facilitate the development of data-driven health**
45 **innovations.**

46 **3. HHS should enhance the HealthData.gov platform's capabilities to make the data more**
47 **meaningful to a range of data customers to extend its reach.**

48 **4. HHS should formalize the governance, stewardship, and business operations**
49 **ofHealthData.gov.**

50 HealthData.gov enables diverse stakeholders including entrepreneurs, health
51 professionals, researchers, policy makers, consumers and community groups to use
52 public data to drive economic empowerment, innovation, and transformation in health
53 and healthcare. By allowing users to more efficiently discover and access publicly
54 available health data in a centralized location, HealthData.gov has become an engine for
55 national and community learning health systems thus furthering HHS's mission at
56 minimal cost.

57 In the attached full report, we include a rationale and specific opportunities for
58 each recommendation. Through its original launch, HealthData.gov spurred healthcare
59 innovation and significantly contributed to the development of an open health data
60 ecosystem; through these recommendations NCVHS has identified specific strategies to
61 increase HealthData.gov's ability to facilitate greater improvement in the value and
62 quality of US healthcare and provide significant opportunities to transform publicly
63 available data to innovate, educate and provide evidence for decision-making to improve
64 the health and well-being of all.

65 In addition to these actionable short-term recommendations to maximize
66 HealthData.gov's potential, NCVHS identified a number of longer-term transformative
67 strategies to enhance HealthData.gov and the data sources that its users connect and
68 access. These fall into areas such as data standardization; data stewardship; developing
69 the capacity to use state-of-the-art technology to accelerate users' ability to understand
70 and develop insights from HHS data; and developing resources for communities to
71 become learning health systems. NCVHS is ready to provide you with additional insights
72 and results that have emerged through this initial analysis and pursue additional ideas
73 related to a long-term vision for HealthData.gov.

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75 Sincerely,

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77 William W. Stead, M.D., Chair
78 National Committee on Vital and Health Statistics

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80 CC: HHS Chief Technology Officer

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